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Experiencing place identity and place belongingness at a children's hospice: Parents' perspectives

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Abstract

Children's hospices are key players in the provision of palliative care services for families with children with life-limiting conditions (LLCs). However, evidence suggests that some of the negative terminology/language which surrounds the notions of palliative and hospice care may contribute to the lack of uptake of hospice services by families. This article reports two elements of place bonding: parents' experiences of place identity and place belongingness at a children's hospice in a region in England. Underpinned by a constructivist grounded theory methodology, focus groups were undertaken with 24 parents of children with LLCs accessing a children's hospice. Despite initial reservations associated with the identity of the hospice, parents described how and why their view changed and therefore consequently how they were able to experience the hospice differently. This article demonstrates how parents' views of the identity of the hospice change and how the hospice becomes a place where parents experience a sense of belongingness.

Keywords

Children's hospice, parent perspective, place belongingness, place identity

Introduction

Many of the terms and language used in the field of palliative care, such as terminal, palliative and life-limiting, can be confusing for parents and for professionals working outside of the field because potentially, they can be interpreted in various ways and mean different things to different

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people (Ling, 2012a). Palliative care is described as an approach to care for children and young people with life-limiting conditions (LLCs) from point of diagnosis to throughout their life and death which encapsulates physical, emotional, social and spiritual elements and which focuses on promoting quality of life for a child and their family (TfSL, 2018: 9). Hospice care and many terms such as those mentioned have also been used synonymously to describe either end of life or the terminal phase of an illness (Boldt et al., 2006; Fadul et al., 2009), and the literature suggests that this may have had an influence on patterns of referral and access to palliative care services (Kirk and Pritchard, 2012; Price et al., 2018; Twamley et al., 2014). Despite this terminological confusion, children's hospices are key places within which palliative care is provided. Since their conception, hospices aimed to offer safe care in an environment that was home-like (Hain, 2019). Indeed, there is a growing literature on the role of architecture in children's hospices in creating a welcoming domesticity while delivering the required health facilities for hospices (Gola et al., 2016).

The concept of place is inextricably linked to people's lives and places as diverse as home (Seamon, 1979), leisure and recreation settings (Gustafson, 2001; Hammitt et al., 2006; Manzo, 2005), coffee shops (Saymanlier et al., 2018) and hospices (Moore et al., 2013) are important to people. There is an increasing focus on children and place, and this work considers how children negotiate different places and the attachments they make to key places that figure within their lives, for example, school (Fleet and Britt, 2011), nature (Cheng and Monroe, 2012) and hospital (Koller and Fraley, 2019).

The work on place that is seminal to the exploration of hospice lies with the work on 'home' or dwelling place, pioneered by Relph (1976) and Seamon (1979). Place is a complex concept drawing on identity, belongingness and attachment. Place identity is a core component of place and refers to the bonds that people form or do not form with a place and it is achieved as people form thoughts, feelings, attitudes, memories and behaviours regarding a specific place (Manzo, 2005; Proshansky et al., 1983). Place identity is also concerned with the notion of belongingness and suggests that it is the social nature of the relationship between place, identity and an individual that in turn ascertains belongingness (Bernardo and Palma-Oliveira, 2016). While abstract knowledge about a place can be acquired quickly, the emotional attachment and feel of a place can take longer to acquire and only be achieved through experiences (Cresswell, 2015). A sense of belonging is linked to Relph's (1976: 49) concepts of 'insideness' and 'outsideness'. Relph suggests that 'insideness' is experienced when a person feels they belong and can identify with a place. The opposite exists when a person experiences negativity towards a place, a sense of not-belonging, perhaps where they feel alienated and therefore an 'outsider'. Adult hospices are places which may be strongly associated with palliative care and this may have extenuated the negative connotations held regarding the perceived identity of children's hospices (Crozier and Hancock, 2012; Himelstein, 2006). There is some evidence that parents have negative perceptions of children's hospices (Pentaris et al., 2018; Twamley et al., 2014), perceiving them to be places of death and suffering. However, while children's hospices do deliver palliative care, including end-of-life care, typically in the United Kingdom, they focus on short-break respite care (Hain, 2019) which is key to supporting parents' ability to cope with the constant demands of caring for a child with an LLC (Ling, 2012b; Swallow et al., 2012; Twamley et al., 2014; Whiting, 2014).

Part of a larger study (Dunbar et al., 2018), the findings reported in this article aim to present the views of parents about their perceptions of the identity of the hospice and their sense of belongingness within the hospice.

Box 1. Four groups/numbers of children with life-limiting/life-threatening conditions in the study (TfSL, 2018).

Category 1 ($n = 1$)	Life-threatening conditions for which curative treatment may be feasible but can fail, where access to palliative care services may be necessary when treatment fails, irrespective of the duration of that threat to life. On reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services, for example, cancer, organ failures of heart, liver, kidney, transplant and children on long-term ventilation.
Category 2 ($n = 9$)	Conditions where premature death is inevitable, these may involve long periods of intensive disease-directed treatment aimed at prolonging life and allowing participation in normal activities. Children and young people in this category may be significantly disabled but have long periods of relatively good health, for example, cystic fibrosis, Duchenne muscular dystrophy and spinal muscular atrophy (SMA) type 1.
Category 3 ($n = 6$)	Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years, for example, Batten disease, mucopolysaccharidoses.
Category 4 ($n = 9$)	Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death. Palliative care may be required at any stage and there may be unpredictable and periodic episodes of care, for example, severe cerebral palsy, complex disabilities such as following brain or spinal cord injury.

Research design

This article reports the experiences of 24 parents of children with LLCs who participated in a larger two-phase grounded theory study (Dunbar et al., 2018) exploring the perceptions, experiences, barriers and facilitators and their influence on the access to one children's hospice in a region in England. During the planning stage of the study, a careful assessment of risk versus benefit was made and strategies identified to protect parents and children. Ethics approval for the study was obtained (14/EM/1004).

Sample and data collection

An opt-in strategy was employed using purposive sampling to recruit parents of children/young people with an LLC (as defined by TfSL, 2018, Box 1) living in one region in England. All parents using the hospice ($n = 258$) were invited to participate. Parents of children specifically accessing 'in-hospice' services ($n = 24$, 19 mothers, 5 fathers) engaged in one of several focus groups held at various locations across the region. The age of the children ($n = 25$, 18 males, 7 females) whose parents participated in the study ranged from 1 year to 25 years (median 14 years), and their primary diagnosis according to the TfSL (2018) criteria is presented in Box 1. Focus groups offered parents the opportunity to talk in detail, explore and share their experiences and perspectives about this sensitive topic with others in a similar situation. All focus group discussions were audio-recorded and conducted by the study's principal investigator (HD).

Data analysis

Following verbatim transcription of each focus group, qualitative analysis software NVivo (QSR) was used to manage and support sorting data into initial codes. Following this, to identify more

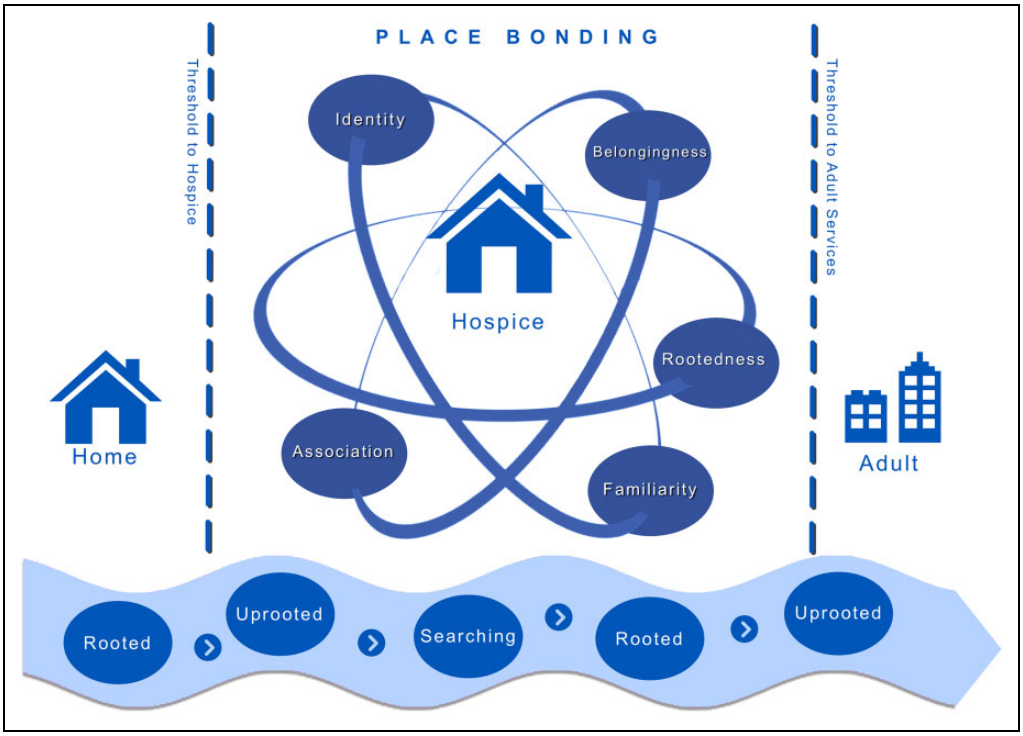

Figure 1. The theory of place bonding within a children's hospice.

focused codes and categories, an iterative process of constant comparison between the data and emerging analysis enabled codes to be sifted, sorted and compared to others identifying relationships, patterns and differences in the data set. Finally, following the three-staged grounded theory method of data analysis described by Charmaz (2014), final categories that represented the experience of the parents in this study were identified and informed the development of a theory of place bonding (Figure 1, Dunbar et al., 2018). The findings in this article focus on two elements of place bonding: parents' experiences of identity and belongingness at the hospice. All quotations presented are anonymised.

Findings

For many of the parents prior to using the hospice for a short break, the word hospice initially indicated that it was 'a place for dying' (P8). The image created by the word 'hospice' generated meanings for some parents that made them reluctant to be associated with the hospice. Other parents explained how they did not admit or talk about where their child was going when at the hospice 'I have never ever once used the word hospice' (P1). Others described the different labels they used to represent the hospice's identity 'we just treat it like a play group', 'it's just [name of child]'s place'. However, for many parents, their view changed after a visit to the hospice, explaining that 'once you go, and actually think, no it's not, it's so much more than a place of dying'. Although it was a place where the initial expectation was tears and sadness, the majority of

the parents using the hospice as a place of respite described it as a place full of 'laughter' and a 'happy place to be' (P9).

Parents reported that there were certain complementary characteristics that worked together to foster a feeling for parents that their child belonged in the hospice and that their child would be looked after appropriately. Many parents described how the assurance of safety and security offered some relief to the parents, for example, one mother described how the hospice was a place that she felt was 'totally safe to leave her [daughter]' (P14). The sense of the need for children to be kept safe and secure by the staff that were caring for them was heightened when children were unwell, one mother said, 'it's knowing what to do in that situation, and obviously only somebody, probably somebody that's worked with him for a while would understand that' (P18).

Parents also described how they wanted consistency from carers who knew their child and understood the intricacies of their child/children routines. Parents wanted staff to pay attention to detail and to 'do things the way (they, the parent) did them' (P24). A few parents described their frustrations when routines were not followed, one mother described how, 'if he comes out of that routine, when he comes home, it takes a week to get him back' (P18). This sense of knowing and understanding their child's routines developed as relationships formed between staff/carers and the child and family. One mother described the 'comfort' and reassurances of 'knowing that there's a good team around you that know your family' (P8). Parents also wanted their children to be cared for by staff who were competent and knowledgeable. This came through when there were consistent carers. One mother described how 'it didn't make sense to her' (P4) to have somebody different looking after her daughter on the Sunday from the Saturday. Parents also had an expectation that staff had a certain level of knowledge:

> There's so many different syndromes, so many different things wrong with each child, you can't you can't expect everybody to know everything about every illness, can you? But, knowledge, some people have to know something. (P17)

When parents were looking for a suitable place for respite, they talked of how the 'the environment has got to be right' (P24). One mother described the environment as one where 'everything is focused on keeping your children happy, and everything else that has to happen, happens alongside that' (P13). This feeling of 'natural', where nothing was forced in the hospice meant that parents felt they had made the right decision in coming to the hospice. The hospice was also a place where the focus was not only on the child with the LLC but also 'the whole family [was] catered for' (P23). Many parents described the support and experiences offered to siblings meant that they too felt part of the 'hospice family'. The hospice provided an enriched environment, in which parents were, in the main, rejuvenated and able to 'catch up' on sleep, and one mother explained how after a good night's sleep she felt 'fresh as a daisy' (P6). Finding 'like-minded people' (P23) to share experiences with and to gain support from was much appreciated.

Finding that the hospice was completely different from their preconceptions came as a pleasant surprise for many of the parents:

> I was expecting it to be like a hospital, but it was like a hotel-hospital, I was just bowled over by what it was like really. (P15)

While there was a pleasing sense that the hospice did not feel like a hospital, some parents suggested that it was because providing care and treatment at the hospice was 'kind of hidden' and

'disguised into normal life a bit more' (P15) or 'done in such a way that you don't really realise that it's going on' (P13). However, while all of this is strongly positive, some parents also described their view that accessing the hospice for respite was not the 'real reason' for the place; there was a flip side to the hospice that meant their child one day would need the hospice for a different reason. Some parents referred to the hospice as having 'two sides', often referring to one side as the 'hidden side', the 'other side of the hospice' (P2). Others referred to a closed door within the hospice acknowledging that 'when you need it that closed door is there for you' (P7). This was an acknowledgement that the hospice could also be a place of sadness and dying. While there was no physical differentiation in space within the hospice, many parents perceived two separate spaces, one where they were happy with respite arrangements and the other space for end-of-life care, a discrete space which they did not need now. At the same time, as describing separate spaces there was a pleasing sense from some parents that there was 'nothing on the outside that really shows what's inside' (P14) and the notion that there was a 'masking the real reason for the place' (P22). However, this was not the case for all parents and there were two parents who found it difficult to reconcile the idea that the hospice was both a place of respite and a place for end-of-life care, arguing that this presented 'a confused offer' (P21). While recognising the 'dual purpose' of the hospice and the fact that it 'operated in two different ways' one mother felt this 'did not always work' (P7).

Many parents described themselves as the 'key worker organising services', 'the carer', 'health manager' or 'nurse' and talked about how constant caring for their child meant they 'just forget who you are, you're doing it without noticing just looking after and you don't think about anything' (P11). There was also a sense of the loss of a treasured role, with one mother explaining 'I don't think you have chance to feel like a mum' (P21). Fathers also struggled with shifts to their identity, one father described how he had become 'two people' one person at work and a 'different person at home', explaining how he felt he was the 'old [name] at work and, new [name] at home' (P19). Respite care meant parents were able to spend time with each other and with their other children, taking part in activities that were often unsuitable for their child with an LLC.

Discussion

Parents' initial negative perceptions are also evidenced in other studies which reveal that, for people unfamiliar with a children's hospice, the terms hospice and palliative care are negatively associated with illness and dying (Boldt et al, 2006; Kirk and Pritchard, 2012; Price et al., 2018). Despite this, the parents' initial reactions toward the hospice were overcome as they developed a sense of attachment and belongingness.

As shown in the literature, the idea of place identity is associated with both positive and negative cognitions (Proshansky et al., 1983; Scannell and Gifford, 2017). Initially, the word 'hospice' framed how parents viewed the hospice as a place. To enter the hospice, parents described having to leave home and cross the threshold (Figure 1). In addition, while there was physically no differentiation in space within the hospice, parents also perceived an inner threshold (Figure 2) and noted that two separate spaces existed; one for respite and one for end-of-life care. Some parents described this as a closed door within the hospice, a door that would not open unless they needed it to, a door which took them to the other side of the hospice, the side for end-of-life care, which they accepted their child would probably need because of their LLC. The threshold or door, described as a 'portal' by Land et al. (2006), albeit in relation to student learning and curriculum design, is a shift in perspective, a way of conceptually transforming and viewing in a

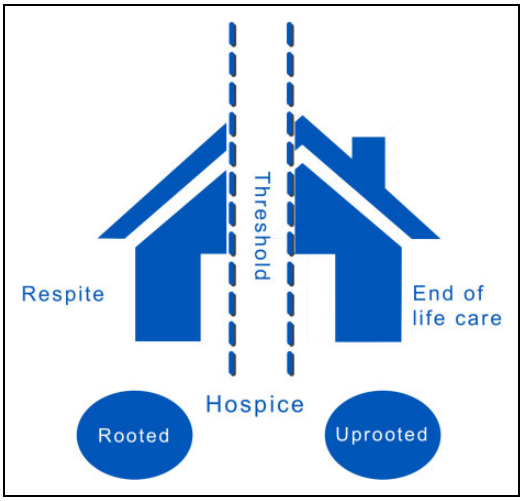

Figure 2. The two sides of the hospice.

different way that which was previously hidden (Land et al., 2006). This shift of perspective was evident with some of the parents. Despite not using the terminology 'palliative', parents recognised that life for their child was limited, and while they did not want to associate the hospice with dying, they did recognise that it was a safe place to be in case their child deteriorated. Other parents, however, continued to choose to view the identity of the hospice primarily in terms of respite; this may have been a disguise/coping mechanism for parents whose child was at the point in their illness trajectory that meant they did not need end-of-life care. It may be that to protect themselves from the notion of death parents were comfortable entering the least threatening side of the hospice.

Relph's (1976) seminal theory of insideness–outsideness provides some rationale for the way in which some parents used this notion of disguise as a way of self-preservation. Entering the hospice symbolised separation for the parents; they were leaving a world where they were familiar and safe, albeit exhausted, but at home to enter a different world at the hospice, one which was confusing and strange and in which they initially experienced a sense of 'outsideness' (Relph, 1976). The hospice is an unusual environment, described by Gola et al. (2016: 49) as a 'hybrid between the complexity of a technological hospital and the presence of psychosocial factors and variables similar to home environments'. Generating a home-like atmosphere, in terms of both the welcome and the feel and the fabric of the hospice, is potentially core to helping to create a sense of attachment. When a place provides the characteristics required to meet individual needs, it is evaluated positively and attachment to place has a role in how people interpret and react to change (Anton and Lawrence, 2016).

The physical environment of the hospice plays a role in whether it is perceived positively as attractive and non-threatening or the reverse (Downing et al., 2014). First impressions count, and it is likely that parents will quickly decide whether the hospice could be an environment that will offer a sense of security and safety for their child. While some children's hospices may be purpose built, others occupy older often quite grand buildings. However, what seems key to making them work is that they are centred on the child and 'dimensioned to human scale and focused on the user

and his needs, care, acceptance and trust' (Gola et al., 2016: 51). In this study, while acknowledging the 'homely' feel to the hospice, several parents expressed that the hospice looked like an office building. However, despite a somewhat bland external architecture, it was evident that there was something about the hospice, a drawing-in affect, which facilitated parents staying. As seen in other studies (Kirk and Pritchard, 2012; Price et al, 2018), the initial apprehension parents talked of in using the hospice was dispelled once they had entered the hospice and quickly began to realise that it was a safe place for them and their child.

The hospice was more than the building, and as suggested by Gola et al. (2016), it was the connections, relationships and trust that were core to parents being able to develop a sense of place familiarity and ultimately form a sufficient attachment to the hospice to allow respite care to occur. Parents needed to know that their child would be cared for safely by staff who had appropriate expertise, knowledge and skills and who could tailor care to their child's individual and unique needs. When their child's needs were met, place bonding appeared to be more likely to happen. Oh et al.'s (2012) work on place bonding tracks the development of strong bonds with a site based on their participants' (anglers) increasing familiarity with the site and the establishment of a greater sense of identity with the site. In a similar way, in this study, parents developed place identity and place familiarity through development of their knowledge of the hospice and reassurance of the skills and knowledge of staff.

The connections that supported place attachment were also supported through their affiliation with other parents and a feeling that the hospice was somewhere where they belonged. This sense of belonging was engendered by being in the 'same boat' as other parents and that their child was with other children with LLCs. Furthermore, this sense of place belongingness was generated through being in a place to which they had a positive attachment; a place where they (parents) and their child were valued and accepted (Hagerty et al., 1992). Positive attachment with places has been shown to be beneficial for aspects of well-being in life (Rollero and De Piccoli, 2010; Sargent et al., 2002) and these places are consciously chosen by individuals depending on how they think the particular setting will satisfy their needs and goals (Raymond et al., 2010). Scannell and Gifford's (2017) exploration of the psychological benefits of place attachment reveals positive effects on memory, emotional support, escape from stressors of life and creation of a feeling of safety, security and belongingness. The humanisation of spaces of care (Gola et al., 2016) allows connections and belongingness to develop, and within our study, the connection the parents had with the hospice grew as their perceptions and images of the hospice changed. Their acceptance of what the hospice offered them meant they were able to acknowledge the paradox of having a deep connection with a place that had both a 'hidden side' as well as being a place of respite that offered them a chance – during respite – to live as 'normal' families. Mothers reconnected with being a 'normal mum' again, brothers and sisters had protected time with parents and families experienced some rest and rejuvenation. In facilitating this move to being a 'normal' parent, the hospice was like a bridge to the life parents had anticipated (Collins et al., 2016; Manzo, 2005) a positive reminder about what life used to be like or what parents imagined life would have been like had their child not had an LLC.

All of the parents who used the hospice expressed a desire for more respite allocation, but the reality was that their stay at the hospice, regardless of the length of duration, was only a temporary situation. As parents experienced and interacted with the hospice more it became more a part of their normal world, one which they missed when they were not there and its meaning and its place identity shifted and grew in significance. The hospice, a place the parents initially feared and did

not want to enter, became a place of belonging, where parents viewed themselves as being part of the hospice family; it gave them a sense of membership of and identity with the hospice.

Conclusions

In this study, a deep-set paradox existed; despite the hospice having an initial place identity representing something that parents feared and a reminder of their child's LLC, as with other studies there was something about the hospice, and its ability to disguise facets of its purpose that made it feel like home-like. Place identity is influenced by a person's experiences in place and how these individual experiences of place in turn inform thoughts, memories and developing identity. A sense of safety, security, familiarity, knowing, continuity of care, trust and relationships within the hospice engendered a home-like sense of belongingness for parents and encouraged them to access the hospice for respite again and again.

Acknowledging the limitations of this study in which recruitment was challenging and which drew only on the experiences of 24 parents at one hospice, we recommend that hospice staff and other health professionals need to act to reduce negative preconceptions and provide reassurance about positive aspects of the identity of the children's hospice as a place of care and belonging. This may be enhanced through earlier recognition and engagement with children, young people with LLCs and their parents about the potential benefits of hospice-based respite care. In turn, this may encourage parents to overcome their concerns about accessing hospice services. Gola et al. (2016: 48) talk of children's hospices needing to be 'prosthetic environments', that is, environments that are purposefully planned to enhance and meet the needs of children, families and staff. Our findings also reveal that only by knowing and understanding the concerns, needs, requirements of children and their families, we can create hospices with a strong, positive place identity and sense of belongingness.

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